

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Interventional procedures

Patient Organisation Submission

Non-cosmetic liposuction in the treatment of chronic lipoedema IP1843

Thank you for agreeing to give us your views on this procedure or operation and how it could be used in the NHS.

When we are developing interventional procedures guidance, we are looking at how well a procedure or operation works and how safe it is for patients to have.

Patient and carer organisations can provide a unique perspective on conditions and their treatment that is not typically available from other sources. We are interested in hearing about:

- the experience of having the condition or caring for someone with the condition
- the experience of having the procedure or operation
- the outcomes of the procedure or operation that are important to patients or carers (which might differ from those measured in clinical studies, and including health-related quality of life)
- the impact of the procedure or operation on patients and carers. (What are the benefits to patients and their families, how does it affect quality of life, and what are the side effects after the procedure or operation.)
- the expectations about the risks and benefits of the procedure or operation.

To help you give your views, we have provided this template. You do not have to answer every question — they are there as prompts. The text boxes will expand as you type, the length of your response should not normally exceed 10 pages.

Please note, all submissions will be published on the NICE website alongside all evidence the committee reviewed. Identifiable information will be redacted.

About you	
1. Your name	XXXXXXXX XXXXX
2. Name of organisation	Talk Lipoedema SCIO
3. Job title or position	Trustee
4. Brief description of the organisation (e.g. who funds the organisation? How many members does the organisation have?)	<p>Talk Lipoedema is a peer-support organisation that aims to support and advocate for people affected by lipoedema in Scotland, and beyond.</p> <p>We currently provide support predominately through our well-established social media presence and web-based resources on Facebook, Instagram, and Twitter, including two private group pages on Facebook, moderated by our volunteers. Recent statistics show that we reach over 3000 women throughout the UK every month, providing peer support, empowering individuals to understand and self-manage their lipoedema.</p>
<p>5. How did you gather the information about the experiences of patients and carers to help your submission?</p> <p>(For example, information may have been gathered from one to one discussions with colleagues, patients or carers, telephone helplines, focus groups, online forums, published or unpublished research or user-perspective literature.)</p> <p>Our organisation was involved in a research study of women's experiences of lipoedema in Scotland. This included in-depth interviews with 5 women who had experiences of liposuction.</p> <p>We have also gathered information through online surveys and informal discussion groups.</p>	

Living with the condition

6. What is it like to live with the condition or what do carers experience when caring for someone with the condition?

From the research study, pain and poor mobility were the key problems for women before surgery.

From our informal discussion group, the recurring topic was the constant frustrating experience of not being respected and believed by medical professionals. Fat bias from both medical professionals and strangers, family, and friends is a daily experience for most women living with Lipoedema. Most of the women expressed a daily struggle with self-confidence, body image, mental health, and disturbed sleep (due to pain)

For the women that are in the later stages of Lipoedema, their mobility is compromised to a level where it limits what type of work they can perform; it's not unusual to have to give up working due to mobility issues and chronic pain. Several of the women reported having had changes made to their housing (having put in stairlifts and walk-in showers) or have had to move to a house that meets their disability needs.

Compression therapy is recommended for the management of lipoedema. Women in stages 3 and 4 reported often needing help from their carers to get into their garments and finding it very challenging to use public toilets for that reason. Getting well-fitted garments is another recurring complaint since some lymphoedema nurses have little knowledge and experience working with people with lipoedema.

Some women have reported that they have been declined highly needed orthopaedic surgeries because their BMI is too high and have been recommended by their orthopaedic surgeon to have liposuction before orthopaedic surgery.

A few of the women in the focus group reported having seen their lipoedema reduce after having gastric surgery. This then enabled them to then go on to have orthopaedic surgery.

Advantages of the procedure or operation

7. What do patients (or carers) think the advantages of the procedure or operation are?

The research study findings showed that overwhelmingly, women who underwent non-cosmetic liposuction experienced significant advantages from the surgery, with improvement in the pain being obvious very soon after surgery and continuing. Also, women found the improvements in mobility very important to their overall wellbeing. Improved pain and mobility were both key in enhancing the quality of life and enabling women to be more active in their home and work lives.

Disadvantages of the procedure or operation

8. What do patients (or carers) think the disadvantages of the procedure or operation are?

Two women in the research study talked of the effects of hypovolaemia immediately postoperatively, which meant they were very lightheaded the first-time bandages were removed post-operatively, and they showered, but this soon passed. Post-operative pain appeared to be well managed and not a significant problem beyond a few days.

In one of the discussion groups, a couple of women pointed out that surgery is not a cure and that there is a risk of regrowth of lipoedema and also the surgery in itself is a risk.

Patient population

9. Are there any groups of patients who might benefit either more or less from the procedure or operation than others? If so, please describe them and explain why.

Those with significant problems with pain and mobility would benefit more as that is a group that would find conservative management of lipoedema very challenging.

That being said, would non-cosmetic liposuction in the early stages be more preventative and would having surgery in the early stages have less impact on one's mental health? Women that have undergone surgery at later stages do report finding it challenging to adjust to their new legs.

"My legs didn't feel like my own for a good 12-18 months, and I look even more unbalanced than before"

Equality

10. Are there any potential [equality issues](#) that should be taken into account when considering this topic?

Gender bias in healthcare generally, where women's health care is not always taken seriously.

Other issues

11. Are there any other issues that you would like the Committee to consider?

We would recommend that surgery is undertaken within the context of a holistic treatment package where people can have conservative treatment before surgery to ensure any oedema is well controlled before surgery. Post-operatively, patients must have access to appropriate physiotherapy, mental health support, compression therapy, and for some, manual lymph drainage, to manage post-operative oedema and enhance a good recovery and long-term outcome.

Key messages

12. In no more than 5 bullet points, please summarise the key messages of your submission.

1. Lipoedema can dramatically impact pain in all stages of lipoedema and cause a reduction of mobility in later stages.
2. It can affect a person's mental health and self-esteem.
3. Non-cosmetic liposuction can have a life-changing effect on mobility, pain level, mental health, and self-esteem.
4. Liposuction procedures must be part of a holistic treatment approach including longer term personalised conservative management approaches such as compression therapy and mental health support.
- 5.

Thank you for your time.

Please return your completed submission to ip@nice.org.uk

Patient organisation submission – July 2021

Non-Cosmetic Liposuction in the treatment of Chronic Lipoedema IP1843

About you	
1. Your name	Sharie Fetzer, Chair – Lipoedema UK, Mary Warrilow, Nurse Consultant Lipoedema UK
2. Name of organisation	Lipoedema UK
3. Job title or position	As Above
4a. Brief description of the organisation	Lipoedema UK is a national patient charity founded in 2011 by women with lipoedema and clinical staff in the Lymphoedema Service at St George's University Hospitals NHS Foundation Trust in London. Our work has supported thousands of women by facilitating greater public and professional awareness and providing objective, up-to-date information on Lipoedema via our website, patient events and our online Health and Wellbeing Community. We also support the medical community, for example through the e-learning course we devised with the Royal College of GPs , and production of 'Wounds UK. The Best Practice Guidelines: The Management of Lipoedema' (2017) . We also undertake and publish surveys, focus group reports, hold an annual conference for both clinicians and patients, and collaborate with key organisations such as the British Association of Dermatologists to raise awareness. Consequently, the condition is now recognised far more frequently than at any other time. We are funded by our 2,500 members and supporters, sponsorship, fundraising, events and donations. We receive no government funding.
5. How did you gather information about the experiences of patients and carers to include in your submission?	We have since our inception collected and collated patient experiences, including a specific survey in May 2021 of 933 women with lipoedema which focused exclusively on non-cosmetic liposuction (NCL) for lipoedema. We reference this survey extensively here, drawing responses from only the 756 participants who said they lived in Great Britain and Northern Ireland. The survey asked 104 questions focusing on diagnosis and services provision, symptoms and impact on quality of life, motivation, pre-and post-liposuction experiences, treatment effectiveness and outcomes and non-cosmetic liposuction complications. There were two main 'pathways' within the survey, depending on whether the respondent had undergone NCL or not. We have also held liposuction focus groups, listened to patient stories and hosted the subject in our weekly <i>Health and Wellbeing Community</i> platform. Five of the six current trustees on our board have undergone NCL for lipoedema. Lipoedema UK patient events enable us to track individual patient experiences, frustrations and disease progression over several years. Our team of Nurse Consultants provide individual support and advice for patients with nowhere else to turn. We have also been privileged to witness at first hand numerous self-funded surgical transformations through our work with outstanding lipoedema surgeons, experts and advisors.

Living with the condition

6. What is it like to live with the condition? What do carers experience when caring for someone with the condition?

Put simply, lipoedema can devastate physical and mental health. Pain, heaviness and discomfort and fatigue are common symptoms. The weight of enlarged limbs and altered gait can lead to secondary joint issues such as osteoarthritis as well as enormous fatigue. Women with Lipoedema are almost always embarrassed by their disfigurement and become quickly demoralised by an inability to lose weight in the areas affected. They frequently become even more disillusioned by the fact that weight loss only seems to accentuate the disproportion between the upper and lower body – a finding particularly evident in larger patients who have undergone bariatric surgery. Low self-esteem and other emotional and psychological issues lead regularly to poor mental health. For many, coping with public and medical stigma of living with lipoedema, and with what many incorrectly assume is obesity, leads to further psychological distress, self-blame, low self-esteem, anxiety, eating disorders and depression. All of the above contribute to the pain of this disease, as well as resulting in lifelong economic costs for both patients and the NHS. As lipoedema progresses, chronic skin changes may develop along with secondary lymphoedema and further disfigurement of the limbs and deterioration, leading to worsening mobility and impaired gait, putting patients at risk of falls. Wheelchair use in the later stages of the disease is common. Fatigue and lack of mobility make everyday chores such as housework exhausting. Public transport can be challenging, if not impossible, and lack of public amenities such as spacious disabled toilets and seating limit social activities, family outings and careers, often leading to isolation. Fitness and exercise options are restricted, also hindered by lack of suitable clothing and footwear and embarrassment and is often exacerbated by inconsiderate/unkind remarks. Many rely on close family members to provide their everyday care. Donning and doffing compression garments over misshapen limbs is particularly challenging and sometimes impossible for anyone living alone. During these later stages, patients will often be at higher risk of repeated episodes of cellulitis, sepsis and hospital admissions. The devastating, negative impact that Lipoedema can have on an individual’s daily life was laid bare in our **2014 Big Survey** and in our most recent 2021 survey: ***Living with Lipoedema – Non-Cosmetic Liposuction and other treatments.***

Findings of the 2021 Lipoedema UK survey - *Living with Lipoedema – Non-Cosmetic Liposuction (NCL) and other treatments*

Living with Lipoedema is likely to cause a negative impact to quality of life (QOL), as the condition affects physical, sexual and psycho-social well-being. It can also cause a financial burden as women are unable to carry on working due to the debilitating effects of the Lipoedema, and because they have to self-fund expensive treatments because of a lack of NHS Services. Some first-person comments from our survey:

“You are always trying to find clothes that fit. You feel ashamed of how you look. You feel people are looking at you and laughing at you. Feel you are judged for overeating even though you’re not.”

“You get to stay on your own as you cannot keep up with family on walks. No sex life as husband finds it repulsive. You loathe yourself. Lonely, sad and depressed. Cannot work, can’t stand too long in one place.”

“Heaviness and swelling are a huge problem – I am only 29 and shouldn’t have such limited mobility”.

Pain and Lipoedema

All participants in our survey, including those that had undergone NCL, were asked about the pain experienced on the day of completing the survey. A Visual Analogue Scale (VAS) was used to rate this pain on a score of 0-10. This was correlated with a verbal descriptive scale, no pain, mild (1-3) moderate (4-6) severe (7-9) and very severe or worst possible pain (10). The British Pain Society (2019) states that VAS can be modified to measure other variables and functions and was also used for rating other symptoms of swelling, discomfort and heaviness. A large number of respondents experienced moderate-severe pain, swelling, heaviness and discomfort. The table (Fig 1.) highlights the results: -

	0	1	2	3	4	5	6	7	8	9	10	N=756
	NONE	Mild			Moderate			Severe		Very Severe - Worst possible		Mod- very Severe totals
PAIN	7%	23%			40%			27%		3%		70%
SWELLING	3%	13%			32%			42%		10%		74%
DISCOMFORT	3%	14%			29%			45%		9%		83%
HEAVINESS	2%	9%			21%			52%		16%		89%

Figure 1.

Other QOL questions were asked and participants were asked how Lipoedema impacted on several aspects and activities affecting of QOL

Our Survey showed that living with lipoedema resulted in many negative aspects to everyday health and activities that many of us may take for granted as illustrated in figure 2. below.

Figure 2. Living with Lipoedema - Quality of Life - 2021 Survey

Physical Health

- 91% had mobility issues with 76% reporting their overall mobility had been *mod-severely* impacted
- 82% stated that their ability to mobilise had been *mod-severely* affected by lipoedema
- 96% experience fatigue
- 95% stated that managing their weight was difficult and had a *moderate-severe impact* on their life with 70% stating that food choice was similarly impacted
- 66% stated that they had difficulty with managing personal care activities such as getting washed and dressed
- 79% stated lipoedema had a *mod-severe impact* to general health
- Almost 100% experienced pain, swelling, discomfort and heaviness in areas affected by lipoedema

Mental & Psychological Health

- 86% reported experiencing Mental Health-Anxiety/Depression
- 97% stated that lipoedema had a *moderate to severe impact* on their confidence
- 97% experienced major issues with self-esteem
- 87% stated that optimism about their future had been negatively affected by the condition

Work and Socialising

- 73% reported lipoedema affected their ability to work
- 72% stated that their long term career prospects had been affected by the living with the condition
- 79% had difficulty with social activities
- 76% stated that lipoedema had a *mod-severe impact* on their ability to enjoy everyday family life
- 43% stating that lipoedema had affected their ability to look after young children
- 91% stated that sex and relationships had been affected by lipoedema
- 58% stating that their ability to manage everyday tasks such as shopping, or housework had been affected
- 100% stated that they had difficulty with clothing, especially finding trousers, underwear and boots that fitted

Work and the financial Burden of living with Lipoedema

Living with lipoedema can make it much more difficult to find and/or hold down a job and achieve financial stability and security. For example, many jobs require wearing a uniform, automatically ruling out such jobs for many women, as they would be unable to find uniforms to fit. Women also tell us repeatedly that they have to pay for private healthcare, having no hope of effective care on the NHS forcing many to take on large debts, perhaps selling or re-mortgaging their homes or businesses to self-fund NCL. They then have to live with feelings of guilt for running up such debts or ‘taking money away’ from their families. These, ironically, are the ‘lucky’ patients - most are simply unable to access sufficient funds for treatment. Some first-person comments:

Privately funding liposuction“It took funds away from my family and children...it was putting a price on my health and quality of life – it felt so unjust.”

“All my life I wanted to be a police officer and joined the service as a Special Constable. I had to give up this dream when my condition started to get worse and I struggled to keep up my fitness due to the pain I was suffering when running.”

“Increasing issues with mobility, depression, ability to mix outside of my home. Not been able to work since 2009 having previously held down a very well-paid position in a large corporate in the centre of London leading to reduced pension as unable to work until government pension age.”

“I gave up my job as a nurse teacher as I was unable to get up off the floor easily. Reluctant to meet friends for walks as get too tired and legs feel heavy. Not doing the fitness classes I used to do, as legs too heavy to lift.”

The Mental and Psychological Impact of living with Lipoedema

Survey responses demonstrate an overall low QOL amongst respondents, with high levels of adverse mental health and psychological symptoms. This is further evidenced in numerous academic studies (for example, Dudek J et al 2021). 49% of women in our survey had been diagnosed with depression with an additional 29% who had not been diagnosed saying they had experienced depression. 24% had also been diagnosed with a general anxiety disorder and 33% had experienced anxiety symptoms without a formal diagnosis. These are significantly greater proportions of such mental health conditions than observed in the population at large, however only 1% of respondents had been referred to psychological services by their clinicians. Some first-person comments:

“Some days have felt suicidal due to this. It’s so life limiting. I will never lead a normal life due to this condition.”

“I feel in a loop of feeling too ashamed to go out, which then impacts my physical and mental health (less outdoor activity, more isolation) and fuels further anxiety about socializing and being judged by others.”

Mobility, Disability and Personal Care Needs

When asked about managing personal care needs, 68% stated that they had difficulty with managing daily care tasks such as getting washed and dressed. Finding clothing ranging from underwear to sportswear to fit their oversized limbs was a massive problem for women, with almost 100% of respondents stating that they had difficulty finding underwear, trousers, and boots to fit. With regard to mobility, 78% of respondents in our survey admitted lipoedema had a moderate, major or severe impact. Everyday tasks such as cleaning and cooking were difficult for 77% of women in our survey. The impact on family members and carers can sometimes be hidden and challenging, when considering how lipoedema affects carers and the needs of carers, we asked respondents – ‘Do you need support to manage your Lipoedema?’ 30% stated they rely on family or friends for care and 8% either have care from social services or self-fund private care. Some first-person comments:

“I have such difficulties getting up and down the stairs, my legs feel so inflexible and life they’re going to give way.”

“Lipoedema impacts my mobility. Wheelchair for distances. Constant pain, so I can’t join in family trips or stand to chat at social gatherings. Due to the mobility impact, I am contemplating leaving work.”

Current treatment of the condition in the NHS

7. What do patients or carers think of current treatments and care available on the NHS?

Women with Lipoedema feel abandoned and are increasingly skeptical that the NHS will help them. Although more and more women and HCPs are now recognising the symptoms of Lipoedema and are looking for services and treatment options from the NHS, such services are most often severely lacking, with a ‘postcode lottery’ existing. Women contact us daily with concerns they cannot even get a diagnosis, and that there are no specialist services locally even if and when they do. The few that are seen in a lymphoedema clinic setting say they receive inappropriate support, and therefore they still struggle to manage their condition and symptoms. This less than adequate situation was overwhelmingly supported by evidence and personal testimonials from our survey.

Getting an early diagnosis of lipoedema is absolutely crucial in preventing its progression, and if some of the worst physical and mental consequences of the condition are to be mitigated. However, far from getting a diagnosis, help and sympathy from health professionals, most women feel they are not listened to. Typically, women are dismissed by GPs, who simply say they are “obese” and “need to lose weight and do more exercise.” 57% of respondents said their GP had not been supportive nor sought out services to help manage their condition. However, 54% stated that they had been referred to a lymphoedema clinic by their GP or consultant, patients needing to visit multiple GPs - or visit their GP repeatedly to self-advocate - before there is a referral outcome. The largest group of respondents (34%) stated that they had been diagnosed by a lymphoedema clinic. Only 16% were diagnosed by their GP, although this was up from the 5% reported in our 2014 Big Survey. 21% had been diagnosed by a Private Consultant or MLD Therapist, indicating a self-funded diagnosis. A small percentage had been diagnosed by specialist services such as dermatology, endocrinology and vascular services. *“They had no clue about Lipoedema and so it took me 20 years to get a diagnosis,”* is a typical comment from our survey.

Figure 3. highlights the huge time gap occurring between Lipoedema symptom onset to patients receiving diagnoses. Almost half of respondents (48%) stated that their first symptoms started at puberty, between ages 11-18. This corresponds with published scientific literature on lipoedema stating that lipoedema starts mostly in puberty, worsening at other times of hormonal change in a women’s lifetime such as pregnancy and menopause (see Buso et al 2019). However, 31% of women are only diagnosed between the ages of 26-40yrs; 29% between 41-50yrs; and 32% get a diagnosis after the age of 50. This time lag is extremely damaging to women’s physical and mental health, personal relationships, family life, career prospects and quality of life. Additionally, women undiagnosed with this genetic condition during their child-bearing years are a) unable to access genetic counselling services to help inform reproductive health decisions, and b) are unaware of the risks pregnancy itself has for their lipoedema and their lymphatic system.

did you notice the first symptoms of lipoedema?										
	0 - 10	11 - 18	19 - 25	26 - 40	41 - 50	51 - 60	61 - 70	71 -80	81 +	TOTAL
At approximately what age...	7.41% 56	48.02% 363	14.95% 113	14.81% 112	7.67% 58	5.56% 42	1.06% 8	0.53% 4	0.00% 0	756
were you diagnosed with lipoedema?										
	0 - 10	11 - 18	19 - 25	26 - 40	41 - 50	51 - 60	61 - 70	71 -80	81 +	TOTAL
At approximately what age...	1.46% 11	1.06% 8	5.29% 40	30.82% 233	29.76% 225	20.77% 157	8.86% 67	1.46% 11	0.53% 4	756

Figure 3.

Non-Cosmetic Liposuction

Access to liposuction within the NHS is extremely limited; it is simply not available to all but a very tiny minority. Yet NCL for lipoedema is what the majority of women want, knowing it is the only intervention that can dramatically improve their symptoms and quality of life.

8. Is there an unmet need for patients with this condition?

Without doubt. Women and HCPs are increasingly frustrated and feel abandoned by the lack of services and treatment options from the NHS. There is no clear clinical pathway from diagnosis/referral through to conservative and surgical treatment options. Neither are there any stand-alone lipoedema clinics. Some lymphoedema clinics offer assessments and treatment for patients with lipoedema but provision is extremely sketchy and increasingly difficult to obtain. The latest directory data show there are only 26 NHS Lymphoedema services with funding for lipoedema patients. Lymphoedema clinics can only offer conservative treatments such as compression therapy which have a very limited effect on lipoedema. In any case, conservative treatments such as compression therapy and Manual Lymphatic Drainage (MLD), which is all lymphoedema clinics can offer, will only have a very limited effect on lipoedema. Referrals to other services such as psychological services or physiotherapy are also lacking. NCL for lipoedema, which has been proven to be effective in several studies, is almost impossible to access on the NHS. Women must nearly always self- fund the procedure. Women not able to self-fund liposuction face increasing despair, seeing only a bleak future of increasing pain, deformity and disability, a lack of social life and increasing dependability on family and friends or the state.

Advantages & Disadvantages of the technology

9. & 10.
What do patients or carers think are the advantages and disadvantages of the technology?

100% of respondents to our survey wanted liposuction for lipoedema to be made available on the NHS:

“I am now getting older, and I have battled so hard to get any sort of treatment to date. I finally reach a diagnosis that fits my symptoms, and everything comes to a full stop because liposuction is seen as ‘cosmetic’. How about thinking how much it can save the NHS if I didn’t need knee replacement, or full-time carers as my size, shape immobilises me, or disability benefits because I can no longer work? The list goes on.”

“To have NCL and the chance of living a normal life! Not worrying about the pain, the heaviness in my arms and legs...not having to worry about the future and how this terrible condition will ruin my mobility, my life and job. Not having the mental stress...this condition affects every aspect of your life, holidays, shopping, leisure activities...you name it, it impinges on it.”

We asked women with lipoedema who had undergone the operation what their reasons were for doing so, details about their procedure, what pre-and post-operative care they received, outcomes and whether they had any post-operative problems. We considered reported benefits and compared the pre-and post-NCL for lipoedema QOL measures.

Motivations

91 women in the survey stated that they had undergone either Water Assisted Liposuction (WAL) or Tumescent NCL. The number of treatments varied from 1-5. The main reasons given by women for having NCL were all related to improving lipoedema associated symptoms. 87% wanting to reduce heaviness in their limbs and 80% to improve overall quality of life and to prevent lipoedema symptoms from deteriorating and disease progression. 70% of respondents stating the other main reasons were to reduce pain, improve the condition and symptoms such as mobility, fatigue, reduce tissue bulk and the size of the limb, to improve their mental health and to avoid lipoedema related health conditions such as joint problems. 40% stated they wanted to reduce their need for care.

Benefits

When comparing QOL indicators pre-and-post-NCL for lipoedema it was evident there were a number of significant improvements in symptoms indicated by the VAS scores reported by respondents following the procedure. (Figure 4). This is supported in numerous studies on the effectiveness of liposuction in treating lipoedema, as previously referenced in this report. We asked respondents who had undergone NCL procedure to complete pain scores based on today (post NCL) and retrospectively pre-liposuction, although we realise this is subjective, the results indicate that there were significant improvements in pain, swelling, discomfort and heaviness scores and improved QOL outcomes when comparing both sets of data.

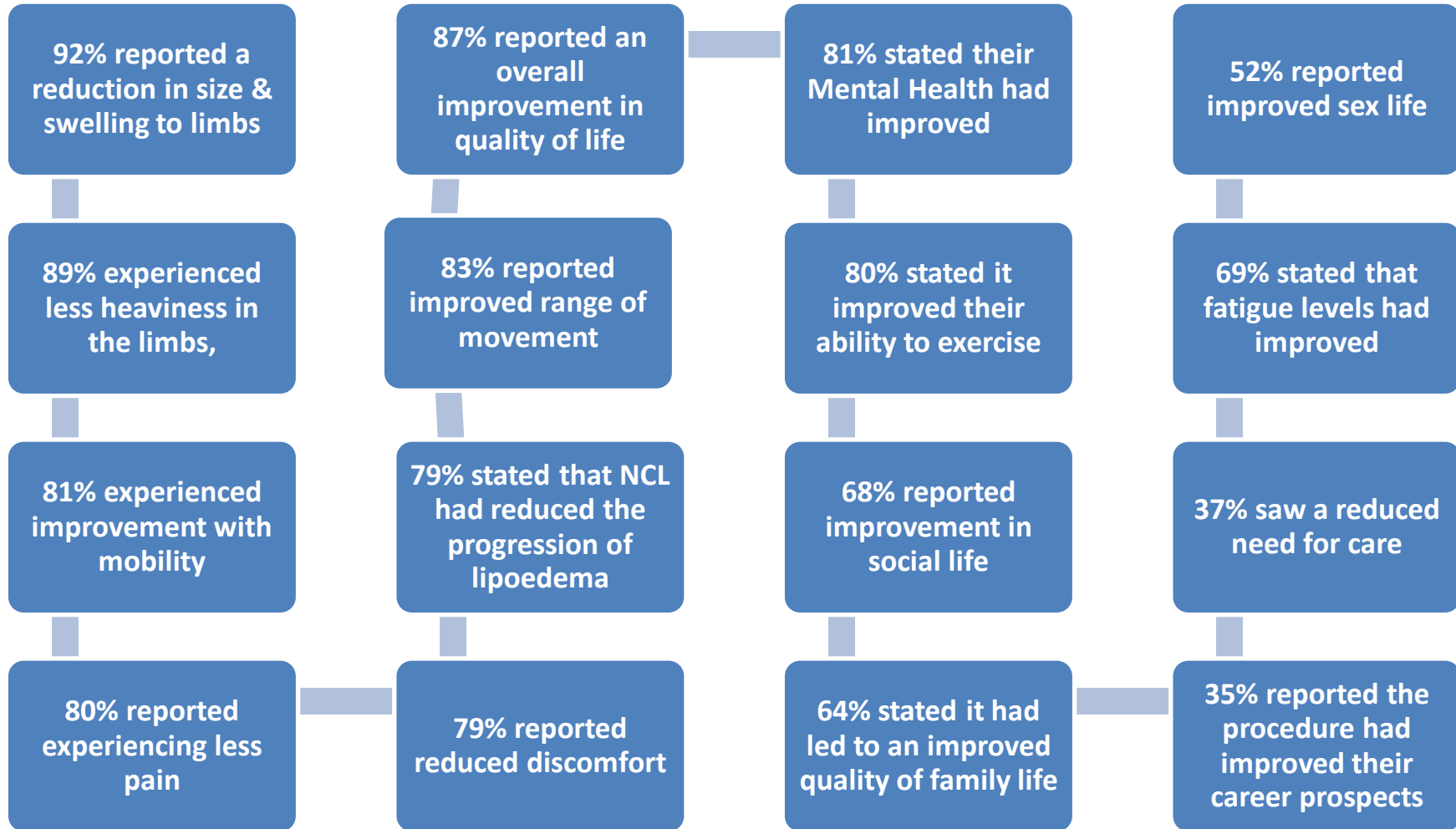
Figure 4. – PRE AND POST LIPOSUCTION VAS SCORES

N= 91 (91 respondents underwent WAL or Tumescent NCL – but only 75 answered this question)

	VAS	0	1	2	3	4	5	6	7	8	9	10		
SYMPTOM	PRE/POST NCL	NONE	Mild			Moderate			Severe			Very severe/Worst possible		Severe to Very Severe totals
PAIN	PRE	5%	9%		19%			53%			13%		PRE NCL = 67%	
	POST	13%	27%		46%			12%			1%		POST NCL = 13%	
SWELLING	PRE	0%	7%		20%			57%			16%		PRE NCL = 73%	
	POST	5%	26%		33%			31%			4%		POST NCL = 35%	
DISCOMFORT	PRE	0%	7%		17%			55%			21%		PRE NCL = 76%	
	POST	10%	24%		33%			31%			2%		POST NCL = 33%	
HEAVINESS	PRE	0%	5%		11%			56%			28%		PRE NCL= 84%	
	POST	11%	21%		31%			31%			7%		POST NCL = 37%	

Other questions relating to the effectiveness of NCL were asked which highlighted significantly high numbers reporting that NCL had been quite or very effective in improving a range of QOL indicators. Also care needs had been reduced due the massive improvement in management of symptoms. Disability had been reversed in some cases with drastic improvements in mobility, pain and heaviness in limbs (Figure 5).

Figure 5. REPORTED BENEFITS OF NON COSMETIC LIPOSUCTION – IMPROVED QOL OUTCOMES



Some first-person comments on NCL from our survey:

"It has changed my life. I could barely walk now I'm in the middle of a nursing degree"

"Surgery definitely helped. I cannot tell you HOW much this would help so many women if it was NHS funded. I am saving myself for more as I can't let it go untreated as it worries me, but I hope one day it will be available on the NHS or for there to be some help, part-funding. Thank you for allowing us to complete the questionnaire and giving a chance to highlight this condition".

"Again, all of these symptoms were unbearable prior to my surgeries. Since operating my life has been changed."

"If performed by the right surgeons it can transform lives and quality of life. Liposuction should be offered early when they Lipoedema symptoms first cause discomfort and begin to reduce QOL so that women can resume a normal life. The benefits at this stage would far outweigh any costs".

"I have had surgery and paid for this. It's made a real difference to my life, physically and mentally!! "

"Being able to walk down a flight of stairs like a 'normal' person instead of lurching from side to side, able to put feet on alternate stairs rather than having to put one foot down, then the next foot on the same step- this happened within days of surgery"

"I cannot express enough how these surgeries have changed my life. I am now regularly exercising and have a BMI under 30"

Disadvantages

Disadvantages were perceived when treatments were received too little too late. People often 'mourn' for the lost years when they realise the additional benefits and outcomes they could have achieved had they received a proper diagnosis, treatment pathways and surgery earlier. The disadvantages of more complex surgical requirements and longer recovery time from delayed treatments along with intervening reduction in QOL was considered particularly stressful.

Post -Operative Complications

Our survey asked questions about post-operative symptoms such as bruising, pain, swelling and inflammation which were commonly experienced up to 12 weeks post operatively. The majority of patients experienced no post-operative complications. However, 21% stated that post op numbness was still experienced 12 months post op, and 46% of respondents still had scars.

14% on women experienced a wound infection and 1% reported developing sepsis post-operatively. 27% of respondents stated 'other' and this included 'blood transfusion, anaemia and seroma. 16% reported a non-healing wound that required dressing, however the survey did not specify the criteria for length of time to qualify to be classed as non-healing.

Our survey asked, “Were you at any time, transferred to, or admitted to, an Intensive Care bed/Unit due to complications following NCL surgery for lipoedema?” 5% stated yes they had, for either a blood transfusion and 1 respondent for ‘sepsis like’ symptoms.

It is important however to put this into context. As NCL for lipoedema is generally not available on the NHS, many women travel overseas for surgery, meaning that they would be unable to contact their surgeon in person if and when post-operative complications do arise. Additionally, it is harder to confirm whether surgeons are adequately qualified to perform liposuction for lipoedema. Patients forced to pay for essential surgery are naturally tempted to choose the cheapest option available, potentially at an increased risk to themselves. Worryingly, some women commented that they found accessing NHS advice and support following private treatment very difficult, despite complications. One patient said their GP practice had refused to remove post-operative sutures, this could be a contributory factor in the incidence of post-op wounds.

When asked how their experience of NCL could have been improved, responses varied from more NHS support, care closer to home, to take away the financial burden of the procedure, NHS availability of MLD (which can significantly aid recovery) and other pre-post care such as psychological support.

Patient population

11. Are there any groups of patients who might benefit more or less from the technology than others? If so, please describe them and explain why.

The Best Practice Guidelines: The management of Lipoedema suggests that individual surgeons will use different criteria for indicating suitability for NCL and will consider other concomitant conditions. Following a comprehensive review, CADTH, the Canadian equivalent to NICE, has concluded that liposuction for lipoedema results in a significant improvement in symptoms and in QOL. The clinical guideline recommends that tumescent liposuction should be considered the ‘treatment of choice’ for patients with a ‘adequate health profile’ but no specific criteria or details of this were given.

Some evidence suggests that liposuction treatment in the early stages of lipoedema provides more long-term reduction in of QOL indicators and a larger decrease in the need for conservative treatments than in later stages (Dadras et al (2017)). The prevention of disease progression could be seen for those having the procedure at an earlier stage, reducing costs to healthcare and individuals, the need for complex conservative treatment and complications seen in disease progression, along with huge improvements in self-esteem and QOL for younger patients. Younger patients (20s) have reported that they believe early NCL treatment has prevented them developing expensive later-life conditions such as eating disorders, depression, obesity and osteoarthritis. Baumgartner et al 2021 (Hanse-Klinik, Germany), Witte et al (2020) and Ghods et al (2021) have published long-term results from NCL demonstrating that the disease most often does not appear to progress or recur following surgery.

Lipoedema UK’s opinion is that NCL treatment in the management of Lipoedema should be available as a treatment option on the NHS and should be considered on an individual basis for each patient regardless of age, type or stage of lipoedema.

Equality	
<p>12. Are there any potential equality issues that should be taken into account when considering this condition and the technology?</p>	<p>The Gender Health Gap: As a health condition almost exclusively affecting women, we can see from the numerous studies and from our own evidence that there is certainly a ‘gender health gap’ when it comes to management of lipoedema. In the government’s recent <i>‘Women’s Health Strategy – a call to evidence’</i> the then health secretary stated that <i>“for generations, women have lived with a health and care system that is mostly designed by men, for men”</i>. This is clearly evident in the case of Lipoedema. Lipoedema UK suggests that withholding potentially life-changing surgery from women is evidence of a clear inequality in women’s health.</p> <p>Medical Bias: Most women with lipoedema report they have been misdiagnosed by their GPs or doctors as overweight. This could be evidence of what some authors have identified as a ‘fat bias’ in healthcare. Even those that do eventually get a diagnosis after decades have been told to ‘just go away and live with it’ by GPs or HCPs who have a poor understanding of the condition. Medical misogyny may contribute significantly to healthcare professionals’ willingness to openly disbelieve and discredit women who report – completely honestly – that their abnormal body shape does not change in response to caloric restriction. When it is wrongly assumed by healthcare professionals that the excessive adipose tissue, heavy lower limbs and body shape is the result of poor self-control and over-eating, rather than caused by disease, feelings of frustration and shame can add to the psychological burden suffered by patients and reduce their willingness to seek medical care for secondary conditions.</p> <p>Socio-economic discrimination: At the moment, those who can afford NCL for lipoedema are able to improve their health. Those unable to pay cannot. Women and families are increasingly forced to take on debt and sacrifice savings or pensions to fund NCL and other treatments.</p> <p>Disability discrimination: Lipoedema causes pain, disfigurement, loss of mobility and may lead to physical, mental, and socio-economic disability.</p>
Other issues	
<p>13. Are there any other issues that you would like the committee to consider?</p>	<p>We have included links to relevant news reports, focus group reports and patient stories from our website and also other evidence that the committee may find helpful in further understanding this complex condition. Please visit our website as there is so much more information available from research papers to news and publications. https://www.lipoedema.co.uk</p> <ul style="list-style-type: none"> • https://www.lipoedema.co.uk/liposuction/ • https://www.youtube.com/watch?v=rCCZFt4AMdl • https://youtu.be/Yi_pw3rO0Ec • https://youtu.be/rCCZFt4AMdl • https://www.bbc.co.uk/news/av/health-47186153 • https://www.lipoedema.co.uk/uncategorized/lipoedema-uks-glynis/ • https://www.lipoedema.co.uk/patient-stories/zoes-story/ • https://www.lipoedema.co.uk/civicrm/mailling/url/?u=29002&qid=216457 • https://www.lipoedema.co.uk/wp-content/uploads/2019/10/LUK-FGR-Liposuction-Web-3.pdf • https://www.lipoedema.co.uk/wp-content/uploads/2019/02/lipoedema-A4-2019-surgery.pdf

Key messages 14. In up to 5 bullet points, please summarise the key messages of your submission

- **The NHS is currently failing women with Lipoedema.** This life-limiting, debilitating disease is almost completely ignored by GPs and Health Care professionals. Lack of awareness and training throughout almost the entire medical community, means women are routinely neglected and misdiagnosed, meaning they suffer unnecessary physical, mental, and psycho-social health and disability trauma. A lack of NHS service provision, any clear pathways for conservative treatments such as compression therapy and a refusal to fund surgical interventions, inevitably leaves women in dire need at risk of worsening health outcomes.
- **Non-Cosmetic Liposuction for Lipoedema can dramatically and positively transform women's health and lives.** Lipoedema UKs '*Living with Lipoedema*' 2021 survey provides clear evidence of Improved Quality of Life outcomes for women who have undergone the procedure. There has usually been a permanent reduction in symptoms and severity and the need for conservative treatments. Significant long-term improvements are seen in patients' physical, mental and psycho-social wellbeing. These positive effects are mirrored in numerous international studies and publications.
- **Liposuction for Lipoedema is a necessary medical intervention: it is NOT cosmetic.** Women with lipoedema do not want 'perfect legs or arms,' they want to be able to live without pain, fear of disability, or worsening disability. They want to protect their mobility, to be able to live 'a normal life.' not become a burden to their family or dependant on the state. NCL surgery can prevent worsening health and therefore plays an important preventative role, reducing and potentially removing longer-term costs to the NHS. The wider benefits of the surgery, not just to a patient's life, but to their family life, career prospects and long-term prosperity and independence are incalculable.
- **Women are being put at greater risk by being forced to self-fund surgery, often overseas.** The risk of greater post-operative complications in this context is obvious, as is the inability of women to be sure surgeons are adequately qualified. Currently, women are seeking out surgeons based on personal recommendations, and may well opt for cheaper options. Lack of UK specialists, regulation and treatment mean that women are often left without proper guidance and access to appropriate aftercare.
- **Liposuction for lipoedema should be available on the NHS.** Liposuction for lipoedema surgery is currently the only known, effective intervention to manage lipoedema symptoms, as evidenced by numerous studies. As a relatively simple, safe and effective procedure with minimal risks to the individual, we trust NICE will make it available to patients on the NHS.

References

Baumgartner A, Meier-Vollrath I., Schmeller W., Hueppe M: Improvements in patients with lipedema 4, 8 and 12 years after liposuction. *Phlebology*; 2021; March vol. 36(no. 2) p. 152-159.

Buso G, Depairon M, Didier T, Wassim R, et al, Lipoedema: A call to Action! *Obesity* (2019) 27, 1567-1576.

Dadras, M, Mallinger P J, Corterier, C, Theodosiadi S, Ghods M, Liposuction in the treatment of lipoedema: A longitudinal Study. *Archives of Plastic Surgery*. 2017 Jul; 44(4): 324–331

Duduk J, Wojciech B, Marcin G., Quality of life, its factors, and sociodemographic characteristics of Polish with lipoedema *BMC Women’s Health* (2021) 21:27.

Ghods M, Georgiou I, Schmidt J, Kruppa P. Disease progression and comorbidities in lipedema patients: A 10-year retrospective analysis. *Dermatologic Therapy*. 2020;e14534.
<https://doi.org/10.1111/dth.14534>

Witte T, Dadras M, Heck FC et al. Water-Jet Assisted liposuction for the treatment of lipoedema: Standardized treatment protocol and results of 63 patients. *Journal of Plastic, reconstructive & aesthetic surgery: JPRAS*: 2020; Sept, vol. 73 (no 9): p.1637-1644.

Wounds UK. *Best Practice Guidelines: The Management of Lipoedema*. London: Wounds UK, 2017.

- Thank you for your time.

Please log in to your NICE Docs account to upload your completed submission

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IP 1843

IP 1843

This report was generated on 02/07/21. Overall 29 respondents completed this questionnaire. The report has been filtered to show the responses for 'All Respondents'.

The following charts are restricted to the top 12 codes. Lists are restricted to the most recent 100 rows.

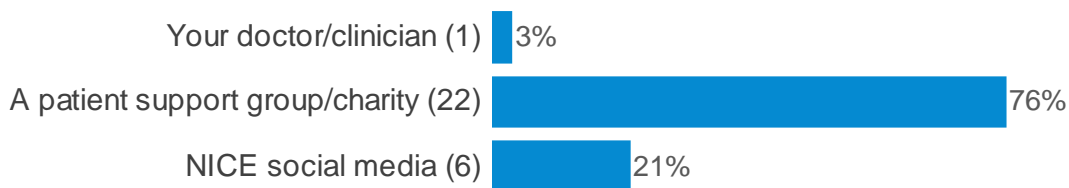
I have read the information above which explains the purpose of the project and how any information I provide will be used



I consent (agree) to NICE using the information I have given in the ways described above



How did you hear about this survey?



Other (please sepcify)

- Lipoedema Facebook group
- facebook
- Facebook group

Are you (the person completing the questionnaire):



Your age (in years)

Count	Sum	Mean	Sample Standard Deviation	Minimum	Maximum	Range
29	1682	58	11.83	26	75	49

IP 1843

How long ago did you have the procedure?

- 5 months ago

- 6 months

- 10 days

- 6

- June and December 2019, February and October 2020

- 6

- in 2019 and 2020

- 2 years

- October 2019

- 6 years

- 2

- I have 4 procedures 2017,2018,2019 and 2020

- 5 years, 2 years ago

- 60 days

- 2

- 4 opps in 4 years

In years

			Sample Standard			
Count	Sum	Mean	Deviation	Minimum	Maximum	Range
15	125	8.33	18.53	0	75	75

In months (OR In months)

			Sample Standard			
Count	Sum	Mean	Deviation	Minimum	Maximum	Range
10	96	9.60	5.25	3	17	14

In months (OR In weeks)

			Sample Standard			
Count	Sum	Mean	Deviation	Minimum	Maximum	Range
0	-	-	-	-	-	-

To which gender identity do you most identify?



IP 1843

Did the procedure work?



If somewhat or no, please provide further details along with information about whether symptoms later reoccurred.

- It has definitely worked, however I have had some growth in my lower legs

- I need more than one surgery

- I have baggy skin and unevenness and numbness, The surgeon stopped in leg surgery due to a big bleed and I suffered severe anemia.

- It did what was promised - removed lipoedema fat from my lower legs. But it didn't improve knee mobility as much as I'd hoped (damage already done to joint over too long a time?) though that can't really be blamed on the liposuction. Also, lipoedema fat piled on elsewhere on my body, especially abdomen. Possibly my fault for not sticking rigorously enough to struct diet?

- I had the back of my upper arms done. The front and lower arms need doing

- The first surgery of liposuction on my lower legs helped me to walk a lot better. No real physical/ cosmetic changes

- Fat removed from both legs from top of thighs to ankles. Fairly pleased but a lot of fat dropped to knees since. Thighs now ok but knees quite large. Considerable continuing bruising in lower legs although lower legs relatively thinner than before surgery.

- Definitely made a difference but also highlighted how much more surgery I needed

- I have noticed it returning in my legs after 2 ops. Arms done recently and they are very uneven although the pain has gone.

- I was advised at the time of the liposuction that I would need a thigh lift. Three years later I desperately need a thigh lift. My skin has stretched and the fat has gathered around my knees.

Did you have any side-effects following your procedure?



IP 1843

If yes, please provide further details along with information about whether symptoms later reoccurred.

Weight gain elsewhere if normal fat and larger breasts due to same issue

Hemotoma and blood clot for full arms and complication from a tiny blister from front of full legs seven and one half liters of lipo fat was removed from full arms and 9 liters from legs

Anemia tacaardia

Nothing serious, just stabbing pains which happened randomly and were due to the nerves recovering, for a few weeks.

I had 3 separate procedures and following the first 2 I needed blood transfusions as I became very anaemic. I also have Lymphoedema in one leg as a result of damaged lymphatic vessels. I also had cellulitis following the first surgery.

Numbness and pain in the area still, uneven fat, loose skin, shoulder pain which I think may be from the surgery as never had shoulder pain previously

I've had numbness in my lower legs and fluid retention. But it's manageable unlike the lipoedema itself. I had blisters following the lower leg surgery which required weekly treatment

I had some trouble with bleeding after my second procedure (on upper legs), I had to be kept in overnight when I was planned to go home the same day; the incision sites bled/leaked more than the procedure on my lower legs and pads had to be changed more often for about two weeks. I have also been left with loose skin above my knees.

Bruising, as above, very bad from start after surgery but have improved somewhat. Skin on lower legs initially seemed'fused'to underlying muscle but less of a problem now.

Numbness, swelling and still need to wear compressions after 4 years

How long did it take you to recover from the procedure?

Not long at all- 2-3 weeks initially then 6 months total

10 days after my operation felt safe enough to drive. Gentle excersise started at 3 weeks and swimming 3 times a week after 1 month post surgery once incision sites were healed.

6 weeks

Still recovering

6 weeks

After both legs about 6 months

I have had 5 procederes legs took about 4 weeks to recover, abdomen 3 weeks and arms 2 weeks

The worst was over by 2 about 4 weeks.

6 months

four months for legs and six monthd from arms

12 weeks

First leg took 10 weeks. Second leg 12 weeks.

1st op front of legs -3 weeks 2nd op back of legs -1 week

From the surgery itself, mostly by about three weeks and almost completely by 6 weeks

A few weeks

The first took about 4 weeks The second and third about 2 -3 weeks.

3 weeks basically, but 2 months completely.

About 8 weeks for healing but still have some numbness in legs after 2 years.

Still recovering

3 weeks+

IP 1843

How long did it take you to recover from the procedure?

3 months

About 3 weeks for swelling to go down and back to full time work. Longer for completely back to normal

4- 6 weeks

10 days to 14 days to feel better then another 2 months to have swelling significantly lower. 4 months to really start feeling like myself again.

Six weeks for the initial incisions, around six months to a year for swelling and numbness.

Physically about 6-8 weeks I was feeling much better.

3 - 4 weeks

Completely 7 to 8 months if you count the numbness which is still present

3 months

How did the procedure positively affect your condition and/or your quality of life?

Please consider things such as:

- Your physical symptoms
- Your ability to perform daily activities
- Your quality of life, lifestyle and/or social life
- Your state of mind, emotional health and/or wellbeing
- The effect on family, friends and others

My legs felt instantly lighter, i had a bit more confidence although still compare my legs to others. Physically less of the dull ache we get.

It has improved my physical by removing 6.9 litres of diseased fibrotic fat from my abdomen and flanks. I can breath without restriction. Also my swimming greatly improved going from 1000m 3 times a week to 1500 3x a week as I can breath much better in the water. I can also cycle again as my abdomen and hips have reduced significantly. 10 inches off my waist and 5 inches of my hips post op. My emotional and mental health has improved slightly as I have at least another 3 surgeries to for as my diagnosis came very late so the disease had progressed to affect most of my body. Since diagnosed I was given the tools to self help through compression garments and diet but because Lipoedema had progressed rapidly in my body due to Menopause I made a positive decision to have liposuction. Family was just relieved that I finally had a diagnosis and liposuction was a step forward to me become pain free.

A lot less pain in lower limbs and upper arms, not bruising so easily, able to hold legs in the air without pain I didn't really have problems with normal daily activities Hard to measure social effects as I have been locked down mostly since my surgery due to COVID, however working out is easier My mental well-being is improved as my body feels lighter and clothes feel better. Family are intrigued at seeing the final results, as many female members have this too.

I am part way through my procedures. I have had one out of three planned procedures. I can already see a huge difference in my appearance and my lipoedema fat has substantially diminished which has helped my well being and also changed the shape of my body. I anticipate when the procedures are completed, I will have less pain (I suffer from extreme pain in my calves mostly).

My physical movement improved. My confidence soared . I was able to do things like I had only dreamed of ie snorkling on the Great Barrier Reef. I

Changed my life in the amount of pain still have some but nothing near what it had been . My confidence went from 0 to way iver 50. Being able to buy iff the peg jeans puts a smile on my face . The heavy bulk no longer there. Exercise isnt as bad dont feel as embarrassed.

Massively reduced pain, not as ashamed to wear skirts. Legs not as heavy and not filling with as much fluid. Easier to buy clothes due to reduced size.

IP 1843

How did the procedure positively affect your condition and/or your quality of life?

Please consider things such as:

- Your physical symptoms
- Your ability to perform daily activities
- Your quality of life, lifestyle and/or social life
- Your state of mind, emotional health and/or wellbeing
- The effect on family, friends and others

Much less pain already, even though I'm only half way through my surgeries. I feel 'lighter' though I haven't lost any weight. I finally feel like I have a future. In all honesty I had reached the point where I was waiting until my parents had died so that I could kill myself. So yes, you could say my mental health has improved.

I feel more confident and I am able to move more easily so allows me to tackle more tasks/activities than before.

No longer any pain or swelling, the horrible heaviness no longer have to cool my legs down after a hot day Can hike and climb stairs again and fit into normal clothing

my ankles and knees are smaller hence I can exercise more easily

Having had the procedure carried out, improved my mobility which was becoming much slower. The pain I was experiencing was greatly reduced. I was finding it more difficult to carry out tasks around the house, due to the pain and slow mobility. My quality of life has improved greatly, I now enjoy clothes shopping, a thing that was never a priority for me, just trying to find something to fit the very heavy fat legs was exhausting. At the age of 61 being able to buy knee high boots was a revelation to me, especially as having gone through life as being labelled as obese. Pregnancy for me was a nightmare, not an exciting time at all. I had been working as a midwife at this time and to be heard by my fellow professionals as obese stayed with me for a very long time. Luckily it did not stop me enjoying motherhood. Diagnosis for me came in my 50's. it was a relief to find out this was a medical problem, and that liposuction could help me. Before that happened though I had a gastric sleeve performed as I felt I had no other option than to have this surgery as my weight was increasing and after various diets, healthy eating, my legs were getting bigger. So I had the gastric surgery, lost a lot of weight but my legs remained large. It came as a huge relief to be told I could be helped. It was a long process to have the surgery performed on the NHS by Mr Munnoch in Dundee. I had trained as a nurse there in the 70's but had moved back to Caithness. Therefore funding had to be approved for me to have the surgery. The only time I'd wished I'd remained in Tayside, perhaps I wouldn't have had to go through the trauma of waiting for funding, as this was not straightforward at all. Following the liposuction. My legs are so much better, my friends have noticed such a huge difference in my appearance and my mood, I'm still working as a staff nurse and the movement I have now is so much better, having struggled for so many years with these very heavy legs. I feel so much fitter. I enjoy going out for walks and doing a little keep fit. Anyone who says liposuction is cosmetic, they really don't have a clue how this disease affects not only the person but those loved ones round about them as well. My husband helped me so much during very low times. I just hope that this disease becomes recognised, in needing surgery and is not seen as a cosmetic procedure.

Surgery increases my mobility albeit I was able to exercise well prior to op as I was stage 2. I was delighted to be able to wear nice trousers and looked good. My family were happy that I had a positive outcome.

Although my surgeries are not completed yet, due to restrictions caused by the CoVid pandemic, I already feel more comfortable walking, my knees don't knock together. I can wear socks and wellies, for the first time in years, because my ankle 'cuff' is much reduced. I can also wear trousers other than 'wide leg', which is much more suitable when walking for fitness, hiking etc. In all, I find that I am able to be far more active, which makes me happier and fitter. I am looking forward to further surgery as and when it is feasible. It has had little effect on any of my family, except my husband, who is much happier that I am healthier and more active.

IP 1843

How did the procedure positively affect your condition and/or your quality of life?

Please consider things such as:

- Your physical symptoms
- Your ability to perform daily activities
- Your quality of life, lifestyle and/or social life
- Your state of mind, emotional health and/or wellbeing
- The effect on family, friends and others

I was able to walk without pain of the very large pads between my knees.. it made me able to walk a lot more and take exercise. I lost more weight because of this and my whole wellbeing was improved. I still have very large thighs and calves and would like another Operation because they are heavy and painful, but feel someone younger who is suffering the desperate unhappiness and stress this condition causes be given the chance to have one over myself. More knowledge in the medical profession of this condition would help those going through the stress and unhappiness this condition causes.

Having had a large amount of diseased fat removed I was able to perform daily exercises, enjoy gardening, and get into clothes that I had been unable to wear before such as jeans. I bought my first ever pair of Wellington boots! Since having surgery I haven't had angina as I wasn't lugging huge legs about. A real positive aspect of going through difficult surgeries. I feel happier with how I look now. For years I had been dieting trying to loose weight but to no avail. Doctors didn't believe me and said I should try harder. Either that or they just didn't want to look at my legs and wonder why my body shape was so different and disproportionate. Now it was my turn to educate health professionals.

Reduced pain, made me able to walk better and further, and be more energetic overall, helped clothes to fit better. Made me happier and improved quality of life.

It has impacted on my life hugely. 22 litres taken from my legs. That has a massive impact on my mobility and my Emotional well being. It must have a positive impact on my internal organs too. My self image and physicality have hugely benefitted in a positive way. I have recently had my arms done and the constant pain has gone. It's too early to say whether It will remain.

Some benefit to mental health as feel more comfortable in clothing. MY ams don't look great but at least I am able to buy clothes that are the correct size for my body instead of having to go 2 or 3 sizes bigger to fit the arms. Less paranoid of people staring at me and seeing the size of my arms. Less weight in ars which had helped posture.

My gait was improved which helped my quality of life. I could walk better

I feel no shame about my legs now. I used to feel ashamed as people used to point at my legs and I used to feel hideous and freakish. Now I feel relaxed about my appearance as I look normal. Not more attractive. Just that I fit it. This has had a knock on effect on my general mental health which was extremely low due to feeling anxious. My mobility is hugely improved. My gait has improved and I can walk better. I was always worried about falling. I would also get leg pain on a regular basis which would stop me being able to walk very far. It's also helped with joint pain. Especially knee pain. Without the surgery the lipoedematous fat would have continued to grow despite diet and exercise and my physical and mental health would have hugely deteriorated So while the outcome isn't perfect as I still have lipoedema in my upper legs I am grateful that I've been able to have it done.

Massively. Increased mobility. Much less pain. Could not walk half a mile. Now walking 4 miles regularly. Even the loss of the ankle cuff meant walking boots could be worn which had a massive impact. Increased confidence- worked with a personal trainer in a gym. Increase mobility has helped weight loss- 4 stone and counting down. Able to join in family outings (used to have to sit on a bench while they went off), much easier to support my elderly parents. Less joint issues - had very bad knee pain and frequent ankle and heel issues- all much better since surgery, probably due to improved gait due to removal of side knee excess fat. My outlook is now positive and I no longer dread the future even though I need further surgery to other areas. My family are keen for me to have more as they've seen the benefits. I have a huge Lipoedema bum which is causing lower back issues. My arms are still growing despite weight loss and are so heavy they are causing shoulder issues.

IP 1843

How did the procedure positively affect your condition and/or your quality of life?

Please consider things such as:

- Your physical symptoms
- Your ability to perform daily activities
- Your quality of life, lifestyle and/or social life
- Your state of mind, emotional health and/or wellbeing
- The effect on family, friends and others

I can walk, cross my legs and even run now. My mobility has greatly improved as has my quality of life. I have been able to continue to work and be active with my family.

I was on the edge of losing my mobility with doctors telling me that they couldn't help. I have regain movement and it has allowed me to get back to my social life, I'm able to perform daily activities, my knee pain has decreased. I still have several surgeries to go before I get fully treated.

I have a lot less pain in my lower legs; I have Ehlers-Danlos as well as lipoedema and the excess weight meant that my knees and hips dislocated more often, however after my procedure this went down a lot. I use mobility aids and devices, but I am able to stand for longer and walk a little more without them. Before the procedure, I had issues with my body image related to the lipoedema fat in my legs, whilst they have not completely gone away they are definitely less pervasive.

Very marked increase in general health. Mobility so much better. Heaviness in legs gone. Could get in/out of cars much more easily. Much more energy, walking much better and faster. No longer so breathless going up steps or slopes. Family noticed great changes in me. Better emotionally and more confident. However lower leg pain was not relieved much.

My personal hygiene has improved (can wipe my bottom a bit better now) and I can lie on my back for the first time in years. Back pain has greatly diminished.

22litres removed from my legs so far, so not carrying that around has got to be beneficial to my mobility And the strain it must have had on my internal organs.The pain has gone and I am abke to enjoy normal activitiess Such as walking and swimming . Idont get as tired and emotionally and psychologically I feel more confident.

Initially my mobility was better and I felt more confident in how I looked.

How did the procedure negatively affect your condition and/or your quality of life?

Please consider things such as:

- Your physical symptoms
- Your ability to perform daily activities
- Your quality of life, lifestyle and/or social life
- Your state of mind, emotional health and/or wellbeing
- The effect on family, friends and others

Negatively it's made me gain a bit of weight and find it harder to lose, and it was extremely costly for my family

The only negative thing I could say after liposuction my husband had to help me on and off with my compression leggings for 3 days.

I haven't had any negative effects since recovering from the surgery it's all been positive

Apart from the extra pressure on my husband to juggle more whilst he is working and the children are at home due to lockdown, whilst I recover there has been no negative affects so far.

None really though not being able to get my arms done due to financial constraints depresses me as I have a small body and legs now but my arm are 3 sizes bigger. But delighted with my legs.

Before liposuction i had 0 confidence i had lost so much weight on upper body but non on bottom this started to put me off. I would not let anybody near my legs or see my legs . Getting boots was out off limits even ankle ones for the snow which meant my ankles were always cold . Still are but not to the extent they were.

IP 1843

How did the procedure negatively affect your condition and/or your quality of life?

Please consider things such as:

- Your physical symptoms
- Your ability to perform daily activities
- Your quality of life, lifestyle and/or social life
- Your state of mind, emotional health and/or wellbeing
- The effect on family, friends and others

There were no negative effects from the procedure however as this was privately funded I was not able to fund enough surgeries to remove all the lipoedema fat therefore the areas that still had lipoedema fat have continued to grow. I had this for 30 years before getting a diagnosis therefore the lipoedema was everywhere.

No

I believe the only negative is that the Lipoedema has grown elsewhere which I think is connected to having my surgery.

NONE

financially baggy skin

I can't say the procedure has had any negative effects for me at all, I just wish I'd known about this disease years before I did.

No substantial negative effects so far

No negative effects.

Apart from trying so hard to get the compression tight measurements correct, which never has been possible, unfortunately, there were no negatives afterwards.

The only negative impact was sustaining damage to my lymphatics particularly in my left leg. This has been shown by a recent lymphoscintogram. However this is a small price to pay. I was told that I would more than likely end up in a wheelchair if I didn't have non cosmetic lymph sparing liposuction. I know I made the right decision to have surgery despite having to fund it myself to the tune of about £30,000.00 as the NHS despite recognising the condition for over 75 years at the time refused funding. My MP did nothing to support my request for exceptional funding which was a huge disappointment.

Slightly sad at the realisation it was not a 'cure' (though I already knew that), and that I might need mire surgery - can't afford it - too old to cope with it and no support to go through it

The cost of the procedures was the huge negative aspect. Apart from it being an unpleasant procedure And takes time to recover, there are only positive effects. It does leave sagging skin but the benefits out weigh Appearance. I only ever had mine for health benefits and NOT cosmetic reasons.

My state of mind is slightly better than before surgery but still has a negative impact on my life as the surgery didn't give the results I was hoping for. Residual nerve pain and the new pain in shoulder are a negative but I don't regret the surgery as the positives outway the negatives

My state of mind was depressed for awhile, since I couldn't "see" any changes in the size of my legs

I had blisters on my shins following the surgery. This was of great concern. I had a 3 month period where I had deep ulcers on my legs. But I think this was a result of the liposuction that could have bern avoided. I have experienced some lymph damage and that causes swelling in my feet and ankles. It's manageable though. I don't see anything negative in removing this painful and debilitating fat.

None after the healing period other than the financial impact of the cost of surgery.

Hasn't negatively affected me other than spell of Cellulitis on my leg whilst one of my legs was healing.

IP 1843

How did the procedure negatively affect your condition and/or your quality of life?

Please consider things such as:

- Your physical symptoms
- Your ability to perform daily activities
- Your quality of life, lifestyle and/or social life
- Your state of mind, emotional health and/or wellbeing
- The effect on family, friends and others

Recovery from it has been hard. This is not for the faint of heart and if I didn't have a medical condition its not something I would have taken on. I know that once I do recover life will be a lot better.

I have had no negative effects that I can think of.

Physically still have poor body image because of bruising and 'lumpy legs' so will not go bared legged or swimming. Because my knees have got fatter I have had a return of joint pain in knees on walking sometimes.

Made me aware of how much surgery I needed in order for a lasting impact. Really just the tip of the iceberg.

In the short term immediately after surgery it took 2 months to fully get up and going but apart from numbness Everything is positive. If you haveoose skin removed you are left with scars but in everyway I feel so much better, physicall, emotionally and psychologically.

Three years on my right leg is so much bigger than the left I am unable to hide it by wearing trousers as my right leg fills my trousers and is so noticeable.

Did you require anymore treatment, including procedures or surgery after this procedure?



If yes, please provide further details.

I have other areas that need doing

I'm I may require an Abdominoplasty in the future.

Yes further surgery to limbs and torso. Manual lymphatic drainage ongoing.

Upper and inner thighs. Microlipo procedures planned for the coming weeks

Yes I need at least possibly 3 more surgeries to my legs and one to my lower back but I cannot afford to have these done. This would virtually remove all my lipoedema fat.

I need MLD therapy after each surgery as part of Complete Decongestive Therapy.

I will need to have a touch up on previously operated areas -only a small touch up.

As already said, my surgeries have been interrupted by the CoVid pandemic. So far I have had the fronts of both legs from ankle to mid-thigh ,done. I am hoping to get the backs done in the next year.

It was suggested I needed 3 operations on my legs. I have had 2 and should possibly have a third at some time. It It has started to come back round my ankles and I have been told that it needs tidying up.

Possibly further liposuction to the areas that were done in 1st surgery and a possible arm lift. Considering lipo of legs at some point too

I had 3 more procedures. The second one also helped my walking. The 3rd and 4th did nothing.

IP 1843

If yes, please provide further details.

I have to have a total of 6 surgeries. I'm on surgery #3.

Further procedures on other places the lipoedema fat stores; upper arms and stomach. I may also in the future wish to have the loose skin above my knees fixed/removed, although this is a cosmetic procedure designed to make my body image issues feel better as opposed to a health-related one.

I was due to return to the private clinic free after one year for follow-on surgery but could not do so due to COVID restrictions. I think this would have sorted out the knee problem.

I would need approximately 6 further surgeries.

I require another procedure on my legs.

Need a thigh lift and possibly more liposuction.

Would you recommend this procedure to another patient with your condition?

Yes (29)  100%

No (-)

If yes, what might you tell them?

If it's what you want to make you feel better about yourself then do it. It's worth it.

Liposuction is life changing, you cannot rid your body of diseased Lipoedema fat and with age the fat becomes more fibrotic and more difficult to remove.

I would say that if they would benefit greatly from this but to make sure that they are fully informed of all of the pros and cons

I had MicroLipo procedure which is a less invasive procedure, has a shorted recovery, can be done under LA or sedation and requires shorter times of wearing compression after the procedure. I would recommend this procedure just because of the results I have experienced with the shorted recovery time.

Go see gp keep going and ask to be referred . If not then keep going . It will change ur luife

It is a hard recovery but so worth it to get some relief from the constant pain. I would suggest it was done at any early stage to remove all the lipoedema fat before it becomes fibrotic. Check the surgeon has an extensive knowledge of working with lipoedema patients and review their post op complications

Do it, as soon as you can, it will change your life.

It changed my life so I believe it works change theirs too.

The physical pain and embarrassment is gone! Improved mobility and appearance! One must watch diet and exercise regularly!

Lose as much weight as possible before the procedure. Expect complications such as small amount being taken due to bleeding

Having surgery at any time is a thought but I would say the best thing ever was for me having the liposuction, the discomfort you feel for a time following the procedure outweighs the good impact it has on life following.

Make sure that your compression is a good fit. I found pain relief and putting ice on areas which were painful greatly helped. MLD is very important a few days after operation.

IP 1843

If yes, what might you tell them?

That the benefits far outweigh the short term discomfort. The worst bit is the wearing of compression hosiery, trying to find a suitably qualified NHS person to measure me for compression has been very difficult here in Somerset. It seems to be a 'postcode lottery', with some people finding it easy, others, like me, almost impossible. The expense of the surgeries is extremely limiting, as it is currently only available privately in England. Mobility issues are vastly reduced, greatly reducing the risk of ending up in a wheelchair in later life.

I would tell them to explain their condition to their GP, taking any information they have on it as most GPs do not know about it. As few can afford the private costs, I was fortunate enough to have it done on NHS and could not praise the consultant and plastic surgeon at St Georges, Tooting enough. It has made it possible for me to walk without pain.

It is no walk in the park! The surgery is complex and the surgeon must be experienced in this specialised technique so do your research carefully. Surgeons in Europe have been undertaking this type of non cosmetic liposuction for years and years. I had my surgery in the UK as I wanted to be home should any complications arise.

do it, its worth it, but its not a miracle cure

That the benefits to your physical, mental and emotional well being is fantastic and that you will be able to move around and free from pain.

I would explain that it had made me feel more comfortable in clothes but they need to be aware the results might not be what you would have hoped for and to research surgeons thoroughly

According to the stage they are in— do it to help you walk. Don't expect physical changes

I'd say without it the lipoedema will not go away. I'd say it's life changing surgery and that I'd have it again.

It is not cosmetic. You will never have beautiful perfect legs/arms but will have improved gait, less pain and can work with thst to improve mobility, fitness and health. It is painful in recovery but this passes. Follow all pre and post op advice. It is definitely worth it. It's life changing.

It is life changing but it is not a simple op and that you need to time to heal and for your brain to come to terms with your new limbs.

From a person that was told by providers for years that there was no hope...these procedures gave me my life back.

I would tell them that the procedure very much helped with the pain and the long-term affects outweigh the short-term issues/healing process.

My experience was overall positive despite the negative aspects. I think it's likely to be more successful in younger women due to greater elasticity in tissues.

It definitely makes a difference but depending on your type and stage of condition a greater impact to your life could be made. I'm at a later stage and my mobility is greatly affected. Once the diseased fat is gone, it's gone.

It removes the pain, it makes you feel fitter and more able to join in normal every day activities. You feel fitter and so are more likely to do more and you dont feel ugly and that everyone is looking at you judging You for a condition you have no control over. The inhibitor is the price.

Listen to the doctor and if a thigh lift is recommended have it done.

If the procedure had an impact on any other areas of your life that are not covered by the questions above please tell us about them here.

Diagnosis made me feel vindicated of being fat due to something that I was doing. There is no other way of getting rid of this Diseased fat.

-

I feel normal and happy, I have a normal looking body! This should not be underestimated.

IP 1843

If the procedure had an impact on any other areas of your life that are not covered by the questions above please tell us about them here.

Financial - time off work and I am now left with numbness

I have worked all my life as a nurse, helping others, but if I hadn't had this procedure I think my working life would have been over, due to the pain, and reduced mobility.

N/A

I was bullied at school for being fat, and left at 14 years old with what is now called an eating disorder, getting very thin on the top part of my body but still large legs. As did my Grandmother and Mother. So when I was told about the condition I had, it gave me a lot more confidence that it was not my fault. Now I am concerned for my granddaughters who seem to have the same shape and I will do all I can to help them and other girls to at least know about this cruel condition. It is not eating too much, it is real.

By having a diagnosis of Lipoedema more than 60 years wondering what was wrong with me has allowed me to see that it isn't my fault and I feel passionate that future generations should not go through what many older ladies have gone through of self loathing, and difficulty in the easiest of activities. It is now apparent that both my maternal grand mother and great grandmother also had this disease was I showed old photos to Prof Mortimer who confirmed this. I am hopeful that my grand daughters should they have the condition will be treated with compassion and be believed when asked about diet etc. Hopefully the NHS will see that by funding a procedure like this it will potentially save costs in the future such as knee and hip replacements and cardiac problems too.

crushingly expensive, meant giving up other things - holiday, new car, any 'treats' etc.

It is so discouraging to save up the money for these surgeries. I even went back to work after retiring. No visible changes and you get depressed/discouraged

It enabled me to stay in full time work as a civil servant contributing to society in service and by paying taxes etc. To me these taxes that would not have been paid had I not had self funded surgery should be used to fund surgery. Keep people moving and they contribute to society. Let their condition go untreated and they become a burden on society.

Mentally feel more positive about my body and I am know able to wear boots to keep my feet dry in winter. It has also opened up a world of clothes that I would not of been able to wear before the operation. I have only had my legs done with Mr Munnoch in Scotland. Sadly my arms have continued to grow and give me a lot of neck pain. So it would be good to get all limbs done.

I am very disappointed that I could not have tithe follow-up surgery on my knees. I am considering whether to have more surgery to rectify this although it would be very expensive and quite daunting. I may not be able to get this free as was promised. I fear that without this my knees will get very much worse.

I hate swimming and showing my legs. I feel everyone is looking at them.
